

## Box 1. One Patient, Two Scenarios....

Selena was diagnosed with heart failure five years ago at the age of 65. Selena and her husband Alex lived in Guelph. Their two daughters lived in Vancouver. So, most of the time, it was just the two of them, taking care of each other.

A year ago Selena started to get sicker. Her appointments with Dr. Baker, her cardiologist, became more and more frequent and she stopped seeing her family doctor altogether.

Six months ago Selena's episodes of shortness of breath became more frequent. She developed pneumonia twice within four months and ended up in hospital three times. Between hospital stays, she continued visiting Dr. Baker. Alex kept a notebook to make sure he was not missing any important information. He was terrified and often felt guilty that he was not taking good care of Selena. He had a feeling that things were spinning out of control.

Selena became more anxious and started thinking about death often. She wanted to be in her own home and spend her final hours with her family but, did not know how to talk about it with Alex, fearing that it would upset him.

Selena was hospitalized again, and over the next two weeks her condition deteriorated. She slipped in and out of consciousness. Alex was by her side. Dr. Baker came in to talk to Alex and told him that there was nothing else they could do. Selena was nearing the end of her life. Alex was devastated. He kept thinking:

"How can that be?! I thought we had more time..."

Selena died in the hospital. The next couple of days were a blur to Alex. It felt like he was sleepwalking.

Alex spent the next week in bed. He did not want to see or talk to anyone. "What is the point? There is nothing left for me."

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Selena was diagnosed with heart failure five years ago at the age of 65. Selena and her husband Alex lived in Guelph. Their two daughters lived in Vancouver. So, most of the time, it was just the two of them, taking care of each other.

A year ago, Selena started to get sicker. Her episodes of shortness of breath were becoming more frequent. She got pneumonia and was hospitalized. The nurse at the hospital connected them with Nicole, a care coordinator from their local Home and Community Care.

The day after the discharge, Nicole called Selena at home. She had already talked to Dr. Ross, Selena's family doctor. Nicole explained that from now on she would coordinate all care and supports for Selena and Alex. A nurse would regularly visit Selena at home. Dr. Ross would continue taking care of her and would consult with Dr. Baker, Selena's cardiologist, whenever that was needed. Nicole gave them two phone numbers: hers and for the on-call nurse in case they needed help in the evenings and on the weekends. Nicole regularly checked with Alex to see how he was doing.

At Selena's scheduled appointment, Dr. Ross said that there was significant damage to Selena's heart. Dr. Ross took the time to explain how her illness would likely progress over the next several months. He worked with Selena and Alex to develop a care plan together. They talked about Alex being the person who would make decisions if Selena was no longer capable. They also talked about where Selena would like to spend her final hours and how their daughters would be informed. Alex felt reassured to know how Selena would be supported and how he could help.

Over the next four months Nicole and the nurse regularly visited Selena. A personal support worker assisted Selena with getting up and dressed in the morning and with taking a bath. Volunteers visited regularly and often spent time with Selena while Alex was taking a nap or going for a walk to clear his head.

As Dr. Ross predicted, Selena was getting sicker. Her shortness of breath was becoming intolerable and medications did not seem to be working. Dr. Ross talked to a palliative care specialist and changed medications to help Selena feel more comfortable. Their daughters came for a visit. As her health deteriorated Selena slipped in and out of consciousness.

Her death was peaceful, at home with Alex and the girls by her side; her favourite song played in the background... After Selena died, Alex had a profound sense of living in a void. At times, he did not want to get out of the bed, but with his permission, Nicole kept visiting. She connected Alex with a grief counsellor. Alex started to open up and talk about his immense sense of loss and about his cherished memories of Selena.